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Supporting Health Among Young Men Who Have Sex With Men and Transgender Women With HIV: Lessons Learned From Implementing the weCare *Intervention*

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Young gay, bisexual, and other men who have sex with men and transgender women with HIV, particularly those who are racial or ethnic minorities, often have poor health outcomes. They also utilize a wide array of social media. Accordingly, we developed and implemented weCare*, an mHealth (mobile health) intervention where cyberhealth educators utilize established social media platforms (e.g., Facebook, texting, and GPS-based mobile applications ["apps"]) designed for social and sexual networking) to improve HIV-related care engagement and health outcomes. As part of the process evaluation of* weCare*, we conducted 32 interviews with intervention participants (*n *= 18) and HIV clinic providers and staff (*n *= 14). This article highlights three key intervention characteristics that promoted care engagement, including that* weCare *is (1) targeted (e.g., using existing social media platforms, similarity between intervention participants and cyberhealth educator, and implementation within a supportive clinical environment), (2) tailored (e.g., bidirectional messaging and trusting relationship between participants and cyberhealth educators to direct interactions), and (3) personalized (e.g., addressing unique care needs through messaging content and flexibility in engagement with intervention). In addition, interviewees' recommendations*

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for improving weCare *focused on logistics, content, and the ways in which the intervention could be adapted to reach a larger audience. Quality improvement efforts to ensure that mHealth interventions are relevant for young gay, bisexual, and other men who have sex with men and transgender women are critical to ensure care engagement and support health outcomes.*

Keywords: *HIV/AIDS; internet/electronic intervention; technology; access to health care; LGBT; minority health; Latino; community-based participatory research; health research*

BACKGROUND

Given the proliferation of mobile devices (e.g., smartphones), mobile health (mHealth) strategies (i.e., medical and public health practice supported by these devices), including social media, offer a powerful approach to HIV prevention and care (WHO Global Observatory for eHealth & World Health Organization, 2011). Social media are widely available, instantly accessible, and relatively inexpensive (Bull et al., 2014; Duggan et al., 2015a, 2015b; Grov et al., 2013; Jenkins Hall et al., 2017; Sun, Garcia, et al., 2015). Young people have particularly high rates of social media use, and commonly used social media platforms among this population include Facebook, texting, and GPS-based mobile applications ("apps") designed for social and sexual networking (e.g., A4A/Radar, badoo, and Grindr; Sun, Stowers, et al., 2015). mHealth interventions may be especially useful for reaching young gay, bisexual, and other men who have sex with men (GBMSM) and transgender women who are disproportionately affected by HIV in the United States, use social media frequently, and have expressed an interest in mHealth HIV prevention interventions (Roberts et al., 2016).

GBMSM represent 70% of new U.S. HIV diagnoses (Centers for Disease Control and Prevention [CDC], 2018). In addition, it is estimated that about 14% of transgender women are living with HIV (Becasen et al., 2019). Racial/ethnic minority GBMSM and transgender women are particularly affected by HIV. HIV rates among youth are also increasing in the United States; youth ages 13 to 24 accounted for 21% of new infections in 2017. These national trends hold true in the U.S. South, the new U.S. HIV epicenter. The U.S. South is home to 14 of the 15 cities with the highest rates of new HIV infections per capita and the majority of new AIDS diagnoses (CDC, 2018). The disproportionate disease burden by young GBMSM and transgender women is exacerbated by low rates of HIV care engagement. It is estimated that about half of people ages 13 to 24 years are aware of their HIV status, and overall only about one quarter are virally suppressed (CDC, 2018). Thus, innovative care engagement strategies are urgently needed.

PURPOSE

Accordingly, our team developed *weCare*, a bilingual mHealth intervention to support HIV care engagement among racially/ethnically diverse young GBMSM and transgender women (Tanner et al., 2016; Tanner et al., 2018). As part of our process evaluation, we conducted interviews with participants and HIV clinic providers and staff.

METHOD

Intervention Overview

weCare, which has recently been added to the CDC Compendium of Evidence-Based Interventions and Best Practices for HIV Prevention (https://www.cdc.gov/hiv/pdf/research/interventionresearch/compendium/lrc/cdc-hiv-weCare_LRC_EI_Retention.pdf), is described elsewhere (Tanner et al., 2016; Tanner et al., 2018). Briefly, we used a CBPR approach to develop and implement an mHealth intervention that harnesses established social media platforms (i.e., Facebook messaging and optional secret group, texting, and GPS-based mobile apps) to improve care engagement among underserved, underinsured, and hard-to-reach racially/ethnically diverse young GBMSM and transgender women with HIV. *weCare* is implemented in English and Spanish by cyberhealth educators who send theory-informed messages using social media to support health across the HIV care continuum. Messages are tailored to participants' unique needs. Messaging is bidirectional; participants initiate conversations as desired. Preliminary *weCare* impact data showed significant reductions in missed HIV care appointments and increases in viral load suppression (Tanner et al., 2018); continued outcome evaluation of *weCare* based on HIV care continuum indicators within medical records is ongoing.

Conceptual Framework

The conceptual framework that guides the content of *weCare* is based on social cognitive theory and the theory of empowerment education. Social cognitive theory emphasizes information, skill mastery, development of self-efficacy, proficiency enhancement, and social support for behavior change/action (Bandura, 1986, 1994, 1997). Thus, *weCare* identifies and fills

knowledge gaps (e.g., expectations of first HIV clinical appointment), fosters skill-building (e.g., scheduling medical appointments), and provides positive reinforcement (e.g., for appointment attendance). Furthermore, empowerment education posits that individuals move beyond learning and critically reflect to "get to" action (Freire, 1970, 1973); thus, cyberhealth educators are trained to use conversation "triggers." For example, cyberhealth educators might applaud a participant who reports getting an antiretroviral therapy prescription, and also ask how the participant plans to get the prescription filled. The cyberhealth educators' social media message library was developed and organized by social cognitive and empowerment education theoretical constructs and by stage along the HIV care continuum (Tanner et al., 2018).

Data and Analysis

Individual interviews were conducted with a random sample of 18 *weCare* participants (nine who were virally suppressed and nine who were not virally suppressed at follow-up) and 14 providers, staff, and *weCare* cyberhealth educators within the implementation clinics. Standardized interview guides (Table 1) explored *weCare* experiences. Interviews were conducted in English or Spanish, lasted 13 to 73 minutes (average = 33), were digitally recorded, and were professionally transcribed (and translated as needed). Intervention participants were compensated $50 for the interviews. Themes were identified through constant comparison, an approach to developing grounded theory, combining inductive coding with simultaneous comparison (Tanner et al., 2016). Team members read and reread transcripts, coded text, and came together to identify, refine, and interpret themes iteratively. Matrices were used to identify similarities and differences within and across interviewees and interviewee categories.

Human protection oversight and approval were provided by the Wake Forest School of Medicine Institutional Review Board.

RESULTS

Participant Demographics

The mean age of the 18 intervention participants was 25 (range: 20–36). About 70% (n = 13) identified as African American/Black and 17% (n = 3) as Latinx. Most participants identified as cisgender men (n = 13), and 25% (n = 5) as transgender women. Participants had been diagnosed with HIV for 2 to 12 years at the time of their interview, with half (n = 9) having been diagnosed for 3 or fewer years. See Table 2 for more detail.

Most of the 14 provider and staff interviewees identified as men (n = 8) with roles including seven care providers (physicians, physician assistants, and nurses), four staff (social workers, patient navigators, and administrators), and three cyberhealth educators.

Qualitative Themes

Our results are organized by three overarching *weCare* characteristics (Table 3): *targeted, tailored*, and *personalized*. Interviewees also provided future intervention recommendations.

weCare *Is Targeted for Diverse GBMSM and Transgender Women With HIV.* Interviewees emphasized the importance of *weCare* being targeted for young GBMSM and transgender women with HIV by using existing social media platforms by real cyberhealth educators with similar demographics, within a supportive HIV clinic.

Use of existing social media platforms. Intervention participants emphasized the value of using social media, given that it was more common than other communication methods (e.g., phone calls). One participant found text messaging more convenient,

> It's just more direct for me. Just tell me who you are and where we're going from there. I feel like that's more professional . . . I was in school. I couldn't answer all the calls, so texting was best. (*weCare* Participant [W]18_22 [age]_cisgender man [gender identity])

Another participant reported intermittent phone service due to financial constraints but consistent internet access, sharing,

> I know, if anything, I'll always have Facebook. There are times when I won't be able to pay my phone bill, and I've had three different numbers since I've met [cyberhealth educator], so Facebook is the best way for me. (W11_21_transgender woman)

Participants also explained that social media communication was useful because it was sometimes difficult to remember information shared verbally by clinic staff, whereas written social media messages could be retained and referred to in the future.

Providers and staff stressed that although they were not able to use social media with patients given institutional limitations, many patients preferred social media communication. As highlighted, "The biggest thing that I struggle with is that I'm not able to text with patients.

TABLE 1
Domains and Abbreviated Sample Items From Interview Guides

weCare intervention participants
Experiences with the *weCare* intervention
What were your overall impressions of *weCare*?
How have your interactions with and on social media changed during and since you began participating in *weCare*?
Relationships with the cyberhealth educators and others
How would you describe your relationship with your cyberhealth educator?
How has your relationship with your providers changed since you began participating in *weCare*?
How have your relationships with your support system (friends and/or family) changed?
Benefits of participation
What have been the primary benefits of participating in *weCare*?
What barriers or challenges to getting and staying in care do you face? What helped you to overcome those barriers/challenges?
How has your interest in getting more information about your health and living with HIV changed since you began participating?
Care management
How have your experiences accessing medications changed since you began participating in *weCare*?
How have your experiences maintaining medication regimens changed?
How have your experiences attending appointments changed?
How important would you say your viral load is to you?
Recommendations for improvement
What recommendations do you have for making *weCare* a better program?
HIV clinic providers and staff
Experience with the *weCare* intervention
Tell me a bit about your experience with *weCare.*
What changes did you notice in the behavior of patients or clients who participated in *weCare*?
Did the *weCare* intervention change anything about your process for linking people to or retaining them in care?
Barriers to viral suppression
What do you see as the major barriers to viral suppression among your patient or client population in?
What do you see as the major barriers among your younger patients or clients? Among your gay, bisexual, or MSM patients or clients? Among your transgender patients or clients?
Recommendations for improvement
In general, what do you think worked well about *weCare*?
What recommendations do you have for making *weCare* a better program?

Note. MSM = men who have sex with men.

But I have a lot of them who say, 'Can't you just text me?' And I can't, unfortunately" (provider/staff [P]06). Another provider suggested that patients who may be considered lost/out of care based may be reachable via social media.

> That's where someone like [cyberhealth educator] could help us out, because then let's say they don't use MyChart [online patient portal], well they might use Facebook or they might use a dating app or something. And then that's where we can engage with them. (P05)

Social media proved invaluable; a cyberhealth educator reported that he was able to engage a participant needing critical care whom providers/staff had been unable to reach by phone. He reported,

> There was this participant who just got diagnosed . . . There was something wrong with his labs so they

TABLE 2
Select Intervention Participant Demographics

Characteristics	M *(*SD*; range) or* n *(%)*
Age in years (n = 18)	25.2 (3.79; 20–36)
Race (n = 17)	
African American/Black	13 (76.5)
White	2 (11.8)
Multiracial	1 (5.9)
Other	1 (5.9)
Ethnicity (n = 18)	
Hispanic/Latinx	3 (16.7)
Non-Hispanic/Latinx	15 (83.3)
Gender identity (n = 18)	
Cisgender male	13 (72.2)
Transgender female	5 (27.8)
Viral suppression (n = 18)	
Virally suppressed	9 (50)
Not virally suppressed	9 (50)

> were trying to call him and he would not answer anyone in the clinic. So his provider . . . asked me if I could track him down because it was a life-or-death situation. He needed to go to the emergency room so I sent him a text message and a Facebook message. He answered me on Facebook, and I started talking to him and explaining to him why they were calling him. So he went to the emergency room and basically that saved his life. (P02)

Participants valued being able to choose their social media platform. Many participants chose Facebook messaging or texting over GPS-based social and sexual networking apps. A participant explained that he was uncomfortable receiving HIV-related messages on the GPS-based apps because,

> It gets too real at that point. When you're on those sites, you're . . . looking for, you know . . . So, it's like, if you're not taking your medication and you're not consistently taking care of yourself and you're on those sites, it's like your parent coming on a date with you, watching your every move almost. (W06_22_cisgender man)

Demographic similarities. Participants were able to connect with cyberhealth educators, who reflected participant demographics in several ways such as gender identity, language, race/ethnicity, sexual orientation, and/or age. Participants emphasized the importance of cyberhealth educators coming from similar racial/ethnic backgrounds, as noted, "It's different coming from . . . somebody of my race, because I can connect with him more" (W13_25_cisgender man). Another participant shared,

> I liked how intimate it is . . . I just graduated college . . . and [the cyberhealth educator] was telling me about what he wanted to do after college . . . it's nice to have people you can relate to. (W18_22_cisgender man)

Providers and staff echoed that these similarities facilitated relationships between patients and clinic staff. A provider stated, "Whatever we can do to make their care . . . more relevant to them and meaningful . . . I'm really excited about that . . . Sometimes, when there's doctor mistrust, if we have young engaging guys, they might trust those other folks. (P08)

Supportive clinic environment. Participants appreciated the strong partnerships between the intervention team and implementation clinics. A participant stated that she felt supported by the clinic, and that the cyberhealth educators played an important role within the clinic,

> I love the clinic. Every time I go there, I feel safe, I feel warm, loved by all the staff and everything. They are friendly, kindhearted and they help me a lot . . . [the cyberhealth educators] help . . . guide the patient. (W16_27_transgender woman)

Another participant reported that the way cyberhealth educators were integrated in the clinic increased his comfort engaging in care,

> At first I was dreading going there . . . But I'm aware that I need to . . . And all the help, messages, and reminders, it's been nice . . . It all helps make my experience better. (W18_22_cisgender man)

Providers and staff shared similar opinions, as noted,

> I just think it's an awesome program . . . It's been a great addition to what we have here in the clinic. When we talk about wraparound services . . . I think this has been one of the biggest things we've done probably in about five years for our patients. So, we love it!" (P09)

weCare *Is Tailored by the Social Media Used.* Participants highlighted the importance of the *weCare* messages being tailored to their concerns by a real person.

TABLE 3
Overview of *weCare* Characteristics and Recommendations for Future Intervention

Targeted
- The value of using existing social media platforms over traditional communication methods (e.g., more commonly used communication strategy and messages can be referred to in the future)
- Cyberhealth educators are "real" people who reflect participant demographics in several ways (gender identity, language, race/ethnicity, sexual orientation, and/or age)
- Intervention implementation within supportive clinical infrastructure

Tailored
- The importance of the messages being bidirectional and not automated
- The importance of a personal relationship between each participant and their cyberhealth educator to guide interactions
- The value of initially meeting the cyberhealth educator in person (i.e., to get to know who is sending social media messages)

Personalized
- Cyberhealth educators identify and address unique needs and priorities based on participants' place on the HIV care continuum and individual disease trajectory

Recommendations
- Logistical and content adaptations (e.g., tailoring frequency of social media communication more to participants' needs, offering informational and instrumental support for non-HIV-related appointments, and ensuring content appeals to nongay-identifying participants)
- Expanding the intervention (e.g., using a broader array of social media platforms, and introducing an anonymous interactive peer-to-peer social component)

Bidirectional messaging. Participants valued that messages were bidirectional (not automated) from someone they had a relationship with, "A computer's not a person that cares . . . [A cyberhealth educator] is a person that cares!" (W09_27_transgender woman). Other participants appreciated the cyberhealth educators' efforts to get to know them. As one participant noted, "Since [cyberhealth educator] was my helper, I know he cared. It was his job and . . . he really got the chance to know me" (W17_22-year-old cisgender man).

Personal relationships helped tailor interactions. Many participants acknowledged the importance of having a personal relationship with their cyberhealth educator, "I don't know if he knew, but some days he texted me, I was going through some things. So just having that person to text and check-up was real big. It was real helpful" (W08_26_cisgender man). Cyberhealth educators facilitated relationship-building with an initial in-person meeting, which was reported as "very important. Like on a scale of 1 to 10, I'd give it a 20" (W11_21_transgender woman). Another participant stated,

> From a human standpoint it is so great for you to really connect with somebody face-to-face instead of somebody you have never seen before or don't know, because you're like, "Who the heck is this person and why are you asking me these questions?" You know? So, it's great that I actually get to put a face to the [messages]. (W13_27_cisgender man)

This meeting helped participants know the real person behind the messages so they could connect and be comfortable asking direct questions.

weCare *Is Personalized to Participants' Unique Needs and Priorities.* Participants appreciated the ways in which *weCare* was *personalized* to their individual needs based on their place on the HIV care continuum.

Intervention participants dealt with many challenges to care engagement, particularly related to processing their HIV diagnosis and their changing needs over time. A participant shared,

> I feel like with time, I'm getting more comfortable with being me. I'm nondetectable and it feels good to almost own it . . . At the beginning I was devastated . . . but I feel like now, more comfortable and open about it. (W06_22_cisgender man)

Newly diagnosed participants had similar struggles, and the cyberhealth educator provided crucial support during this time, as noted,

> That was the best thing with me, the bond . . . Like my doctor, [the cyberhealth educator] was the biggest thing to me. Because when I first found out about my status, I'm not going to lie, I wanted to commit suicide. I literally stood on the bridge, "I'm gonna jump." (W10_27_cisgender man)

This early connection with the cyberhealth educator was clearly critical.

Providers and staff also recognized the utility of the relationships between participants and cyberhealth educators following diagnosis,

> There have been some individual cases where patients new to clinic have been very successful in coming to clinic, and I think their interactions with the [cyber]health educators was part of the reason. They were very helpful in the . . . beginning stages for people, making sure they made it to visits and communicating with them. (P10)

Having real people behind the messages, facilitated *weCare's* ability to get current needs addressed at the beginning (care linkage) and over time (care retention).

Recommendations. Overall, intervention participants and providers and staff had positive perceptions of, and experiences with, *weCare*. For instance, one participant stated, "Honestly, [*weCare* is] the best thing that ever happened!" (W11_21_transgender woman). Many did not have suggestions for improvement, as highlighted,

> I don't really have any recommendations. I just like *weCare.* Making sure they're okay, just checking up on people. That is a really big thing with me. As long as they keep doing that, I love it! (W10_27_cisgender man)

Other participants provided recommendations to improve future *weCare* iterations. Most recommendations focused on logistics, content, and the ways in which *weCare* could be adapted for a broader reach.

Logistical and content recommendations. Some of the specific logistical recommendations focused on the frequency of communication, such as,

> If they wanted to [text] more, that's fine with me. If they want to text every day, that's fine with me. But, you know, just twice a week, that was cool for me. I was just touched that they actually care, and were worried, and were making sure I was okay. (W10_27_cisgender man)

Other suggestions focused on offering informational and instrumental support for non-HIV-related appointments (e.g., mental health) and ensuring that content appeals to nongay identifying participants (e.g., broader community events).

Expanded intervention research. Specific ways to broaden *weCare's* reach included using a broader array of social media platforms. One participant noted,

> Everybody's on Instagram now. Even Twitter, I feel like, even if it's not for the people that are a part of the program, but maybe to educate others that are willing to follow . . . Any kind of information to get out there for those that don't know, so beneficial. (W06_22_cisgender man)

Furthermore, noting that participation in the secret Facebook group was low, one participant recommended having an anonymous interactive peer-to-peer social component,

> A GroupMe or whatever those apps are that you can all communicate and have a thread or blog or whatever, I think that might be more secure to make people want to post their opinions and their experiences and their situations. (W01_21_cisgender man)

DISCUSSION

mHealth interventions for HIV care engagement can ensure broad and confidential reach to young GBMSM and transgender women with HIV (Mbuagbaw et al., 2015; Muessig et al., 2013; Rana et al., 2016; Saberi et al., 2016; Taggart et al., 2015). Our work highlights the importance of providing theoretically informed messages that are *targeted* to diverse young GBMSM and transgender women using existing and preferred social media, *tailored* through bidirectional messaging from a "real" person with whom participants have a relationship, and *personalized* to participants' changing needs and priorities along the HIV care continuum.

Participants reported many strengths of *weCare*. First, *weCare* uses existing social media platforms that young GBMSM and transgender women already use. Thus, the behavior change focused on HIV care engagement, not the use of a new app as an antecedent behavior. This use allowed the cyberhealth educators to contact participants in ways that the implementation clinics could not (in one case saving someone's life). Second, the messages

were bidirectional, which allowed participants to drive the content of messaging based on their unique needs and priorities as opposed to generalized and assumed needs and priorities. This approach to meeting each participant where they are is respectful and particularly important given the disease burden carried by young GBMSM and transgender women. Third, the intervention "dose" can be tailored to the participants' changing needs over their disease trajectory. Participants expressed greater needs at time of HIV diagnosis (e.g., for coping with diagnosis) and fewer needs as care behaviors became routine and they become more comfortable with providers. Yet barriers to HIV care can be cyclical (e.g., unexpected illness and loss of job; Wohl et al., 2017; Yehia et al., 2015), and the relationship participants had with their cyberhealth educators allowed them to feel comfortable to reach out for assistance during those times. Overall, participants had positive assessments of *weCare*, with recommendations focused primarily on implementation logistics, intervention content, and intervention expansion. Fortunately, *weCare* is flexible and can be adapted and used on additional (and new) social media platforms, making it less likely to become obsolete than native apps.

Limitations

A few limitations should be noted. Intervention participants who agreed to be interviewed may have had a more favorable perception of *weCare*. Notably, not all were successfully managing their HIV (e.g., half not virally suppressed), so we could discuss ways to address their continued needs. This work was also done in the U.S. South with a large rural clinical catchment area within a supportive environment. Other geographic regions may have different HIV-related care resources and clinical policies that could affect implementation of an mHealth intervention.

Implications for Policy and Practice

Innovative intervention methods are needed to meet the End the Epidemic goals (CDC, 2019) of reducing HIV incidence and prevalence, particularly among young GBMSM and transgender women who carry a disproportionate HIV burden.

While many clinics have existing portals for patients to access medical records and to communicate with provider teams, portal use is low among some populations who prefer to communicate directly via familiar social media platforms with a known person on the other end. The impersonal feel of clinic portals does not encourage use among some, especially underserved, underinsured, and hard-to-reach racially/ethnically diverse young GBMSM and transgender women with HIV.

Incorporating mHealth interventions, like *weCare*, into standard HIV clinical practice, including through specific clinic policies (e.g., allowing social media communication with patients), is crucial to health promotion among young GBMSM and transgender women with HIV. *weCare* was specifically designed for those who are most at risk for being unsuppressed; however, it may be useful for broader clinic populations of persons with HIV, such as older persons and women, and for HIV prevention (e.g., PrEP navigation).

The flexibility of the *weCare* intervention suggests the potential for further adaptation and expansion. Given the ability to implement on new and different social media platforms, *weCare* can continue to be relevant as technologies develop. Furthermore, the strategies used in *weCare* may be transferable to other settings, including internationally, where different social media platforms may be more common, and in lower resource contexts, given increasing accessibility of smartphones and other mobile devices. Finally, lessons learned from *weCare* may be applicable to increasing care engagement within other health areas, such as chronic disease management, particularly among young people. Further research and practice in real-world settings can continue to explore these possible uses of mHealth to support improved health outcomes and reduce health disparities.

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